Received: 21 March 2022 | Accepted: 2 September 2022

DOI: 10.1111/dmcn.15421

ORIGINAL ARTICLE

Real-time daily fatigue, sleep, physical activity, and health-related fitness in adults with cerebral palsy

Olaf Verschuren[1,*] | **Joyce L. Benner**[2,*] | **Astrid C. J. Balemans**[1,2,3] | **Herwin Horemans**[2] | **Rita Johanna G. Van Den Berg-Emons**[2] | **Wilma M. A. Van Der Slot**[2]

[1]Center of Excellence for Rehabilitation Medicine, Brain Center Rudolf Magnus, University Medical Center Utrecht, Utrecht University and De Hoogstraat Rehabilitation, Utrecht, the Netherlands

[2]Department of Rehabilitation Medicine, Erasmus MC, University Medical Center Rotterdam, and Rijndam Rehabilitation, Rotterdam, the Netherlands

[3]Department of Rehabilitation Medicine, Amsterdam Movement Sciences, Amsterdam Public Health, Amsterdam UMC, Amsterdam, the Netherlands

Correspondence
Olaf Verschuren, Rembrandtkade 10, 3583TM Utrecht, the Netherlands.
Email: o.verschuren@dehoogstraat.nl

Funding information
Fondation Motrice

Aim: To explore whether subgroups of adults with cerebral palsy (CP) with different fatigue diurnal profiles can be discerned, and to explore whether sleep, physical activity, or health-related fitness are associated with these profiles.

Method: Thirty-two adults (median age 29 years 8 months; range 20–54 years; 11 males, 21 females) with spastic CP (Gross Motor Function Classification System levels I–III) with physical activity-related fatigue complaints participated. Real-time fatigue and physical activity were assessed for 7 consecutive days by short message service text four times during the day and by wearing an accelerometer respectively. Sleep was assessed by the Pittsburgh Sleep Quality Index, and fitness by assessing body composition and aerobic capacity. Latent class growth modelling was used to classify subgroups according to their diurnal profiles of real-time fatigue. Univariable multinomial logistic regression analysis explored whether participant characteristics, sleep, physical activity, or health-related fitness were associated with diurnal profiles.

Results: Three distinct fatigue diurnal profiles were identified: stable low ($n = 10$), increasing ($n = 14$), and stable high ($n = 8$). Only aerobic capacity was associated with fatigue profiles (odds ratio 1.15, 95% confidence interval 1.00–1.34; $p = 0.05$).

Interpretation: Fatigue in adults with CP may be low or high stable or may increase during the day. These findings indicate the relevance of assessing fatigue variability.

Fatigue is a common health issue for people with cerebral palsy (CP). It has been estimated that up to 40% of adolescents and adults with CP experience fatigue.[1–4] Together with pain and joint deformities, fatigue is one of the most important impairments in people with CP and seems to emerge in adulthood and worsen over time.[5] Furthermore, fatigue is known to impact quality of life and daily activities.[1–4]

Fatigue is multifactorial in nature, with physical and mental components. The way people perceive fatigue or cope with it varies.[6,7] Clinical experience shows that in CP, a complex and heterogeneous disorder, many factors may potentially play a role in fatigue, such as cognitive dysfunction and muscle characteristics, medication side-effects, higher frequencies of depressive feelings, physical (in)activity, and sleep disturbances. The nature of fatigue appears hard to unravel by those who experience it, as well as by measurement instruments. So far, literature is scarce. A Dutch study showed that various components (general, mental, and physical) of

Abbreviation: RTFS, real-time fatigue score

*Shared first authorship.

fatigue were higher in persons with CP than in a reference sample.[2] In a Norwegian study, however, adults with CP reported significantly more physical but not more fatigue than the general population.[1] The authors suggested that fatigue in persons with CP is primarily a physical symptom and/or of physical aetiology.[1] This is supported by Pimm et al. who discussed the theory of 'physiological burn-out', caused by an imbalance between physiological strain and physiological resources over time.[8] In addition, adolescents and adults with CP also reported physiological factors (i.e. poor sleep quality) as the most common contributors to fatigue.[9]

In different populations, it is shown that fatigue varies during the day (e.g. fatigue being less severe in the early morning than in the afternoon).[10,11] Specifically, in a complex disorder such as CP, different fatigue patterns may be expected. Detailed information on fatigue patterns may help to unravel fatigue and advise people with CP on fatigue management (e.g. balancing rest and activity, and fitness training). Real-time diurnal assessment of fatigue can be used to monitor an individual's experience of fatigue during the day. This is done by immediately responding to the question of how fatigued one is at that particular moment. Immediately responding to a question is easier and has the benefit of avoiding recall bias. Consequently, patient-reported outcomes may become more accurate. Real-time diurnal assessment of fatigue may be especially valuable in people with CP experiencing cognitive dysfunction (e.g. memory or attentional dysfunction).[12,13] Furthermore, knowledge of diurnal profiles of fatigue may provide another perspective on fatigue in adults with CP.

To date, there is limited and inconclusive information about factors that may be associated with fatigue in adults with CP. In one study, low levels of physical activity, but also higher body mass index (BMI), as a health-related fitness component, were associated with fatigue in adults with CP.[4] Another study of adolescents and young adults with CP, however, found that daily physical activity and BMI were not related to fatigue; a trend was found for the association between aerobic capacity and fatigue.[3] In both these studies, fatigue was assessed by self-report questionnaires that might explain the inconclusiveness.[14]

Real-time diurnal data regarding fatigue in persons with CP is lacking and the physiological mechanisms behind fatigue in adults with CP are unknown. In the present study, our primary aim was to explore real-time diurnal fatigue profiles in adults with CP. Our secondary aim was to explore whether sleep, physical activity, and health-related fitness could predict these profiles.

What this paper adds

- We found three patterns of daily fatigue in adults with cerebral palsy (CP).
- Only aerobic capacity was associated with fatigue profiles in adults with CP.
- Moment-to-moment variations in fatigue can help with personalized fatigue management.

METHOD

Participants

Participants were recruited through De Hoogstraat Rehabilitation in Utrecht and Rijndam Rehabilitation in Rotterdam, the Netherlands. Physicians invited the participants once eligibility was determined and interest to participate was expressed. Ambulatory adults with CP with complaints of fatigue during daily activities such as walking or cycling, complaints of reduced walking distance or speed, and those with limited ability to perform intensive physical activities were eligible for this cross-sectional multicentre study. Other criteria for participation included: (1) diagnosed with spastic CP according to the Surveillance of Cerebral Palsy in Europe;[15] (2) 16 to 60 years of age; (3) classified in Gross Motor Function Classification System (GMFCS) - Expanded and Revised levels I to III (able to walk with or without assistive devices);[16] (4) no contra-indication for maximal exercise; (5) no severe communication or understanding problems that impede proper measurement performance; and (6) no history of botulinum neurotoxin A injections and/or serial casting in the past 3 months or surgery in the past 6 months. The study was approved by the Medical Ethical Committee of the University Medical Centre Utrecht, Utrecht (the Netherlands) and the Erasmus MC, University Medical Center, Rotterdam (the Netherlands), and participants signed informed consent before participation.

Procedure

Participants visited the outpatient clinic for a laboratory assessment. The participants were given specific instructions to not eat or drink (except for water) 1.5 hours before the measurements, and to not perform intensive exercises 24 hours before the measurements. First, body composition (BMI and fat mass) was determined. After a rest of at least 15 minutes, the participant performed a progressive exercise test on a cycle ergometer to determine the aerobic capacity. At the end of the lab assessment, an activity monitor was placed on the frontal thigh to wear day and night for 7 consecutive days to determine physical activity. During this week, real-time fatigue was simultaneously assessed by short message service (SMS) text. On the 7th day of the same week, participants were asked to score their sleep quality using a self-report questionnaire.

Outcome measurements

Fatigue

The outcome of interest was real-time fatigue assessed daily for 7 consecutive days. Participants received a SMS text on their mobile phone with the following question: How fatigued do you feel at this moment? These messages were sent at four different time points during the day (9 am, 1 pm, 5 pm, and 9 pm). Participants were asked to rate their fatigue from 0 (no fatigue) to 10 (severe fatigue). Furthermore, an overall real-time fatigue score (RTFS) was derived by averaging the seven scores at the four time points. Hacker et al. defined patient-reported real-time fatigue scores with intensity scores ranging from 0 (no fatigue) to 10 (worst) as follows: a score of 0 was defined as no fatigue; scores of 1 to 6 as (low to the high end of) moderate fatigue; and scores of 7 to 10 as (low to the high end of) severe fatigue.[17]

Predictors of interest consisted of individual characteristics or physiological predictor characteristics: (1) sleep quality, (2) physical activity, and (3) health-related fitness.

Sleep quality

Sleep quality during the previous month was assessed using the Pittsburgh Sleep Quality Index,[18] a 19-item self-rated questionnaire. The items are grouped into seven components (subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleep medications, and daytime dysfunction), each yielding a score ranging from 0 to 3. The sum score ranges from 0 to 21 with higher scores indicating worse sleep quality. Good and poor sleepers were distinguished by a Pittsburgh Sleep Quality Index score higher than 5. The Pittsburgh Sleep Quality Index has a high degree of internal consistency (Cronbach's $\alpha = 0.83$), and good test–retest reliability (intraclass correlation coefficient = 0.85).[19] Regarding validity, the Pittsburgh Sleep Quality Index identifies between good and poor sleepers.[19]

Physical activity

Physical activity was measured using the Activ8 Physical Activity Monitor (Activ8 device; 2M Engineering, Valkenswaard, the Netherlands). The Activ8 is a small, lightweight one-sensor device containing a triaxial accelerometer, and has shown adequate criterion validity in the detection of physical activity in adults with CP.[20] The Activ8 software (Activ8all.com) classifies lying/sitting, standing, walking, running, and cycling. These postures and movements are determined from (1) the angular position of the device with respect to the line of gravity and (2) the variability of the signal, which depends on the intensity of the movement. Participants wore the Activ8 on the front lateral thigh of the least affected leg for 7 consecutive days and were asked to participate in their normal activities. Data for physical activity were included in the analysis when at least 11 waking hours were registered per day, with a minimum of 3 days. The time spent in physical activity (standing, walking, running, and cycling) was calculated and averaged over the included days.

Health-related fitness

Measurements of health-related fitness comprised two body composition measures (BMI, fat mass) and aerobic capacity. To determine BMI, height (cm) was measured with a wall-fixed measure in a standing position. In case of difficulties with standing position or contractures, height was measured in a lying position with a hand-held measure. Weight (kg) was measured using electronic scales (DGI 250D, KERN DE version 3.3 10/2004; Kern & Sohn GmbH, Balingen-Frommern, Germany). Fat mass (%) was determined with bioelectrical impedance analysis (Bodystat Quadscan 4000; Euromedix, Leuven, Belgium), a non-invasive test comparing conductivity and resistance in the body to distinguish lean body mass and fat. Oeffinger et al. stated that bioelectrical impedance analysis for people with CP is very accurate and can be used to assess body composition in this population.[21] Aerobic capacity (VO_{2peak}) was measured during a maximal exercise test on a bicycle ergometer (Corival V2 [Lode B.V., Groningen, the Netherlands] in Utrecht and Jaeger ER800 [Jaeger Toennies, Breda, the Netherlands] in Rotterdam). VO_{2peak} was measured with a mobile gas analysis system (Metamax 3B system [Cortex, Metamax, Leipzig, Germany] in Utrecht and COSMED k5 [COSMED, Rome, Italy] in Rotterdam). The maximal exercise test consisted of a progressive ramp protocol to maximal exhaustion. During the exercise testing, the participants were asked to maintain a cadence of 60 to 80 rotations per minute. The exercise test was terminated by volitional exhaustion, cadence lower than 45 rotations per minute, or, for safety reasons, compliant with the American College of Sports Medicine's guidelines for clinical exercise testing.[22] The test started with a warm-up phase of 3 minutes pedalling at minimum resistance (0–5 watts) followed by an exercise phase with increments of 2 to 6 watts every 12 seconds depending on sex and GMFCS level.[23] VO_{2peak} (ml/kg/min) was the highest VO_2 over 30 seconds, which was used as a measure for aerobic capacity.

Statistical analysis

Statistical analyses were performed using SPSS version 25.0 (IBM Corp., Armonk, NY, USA) and Mplus version 7.11 (Muthén and Muthén, Los Angeles, CA, USA). Sample characteristics and mean scores or frequencies of outcome and variables were reported for descriptive purposes using SPSS. All continuous variables were checked for normality using one-sample Kolmogorov–Smirnov tests; mean and standard deviation (SD) or median and interquartile range (IQR) are reported accordingly.

Fatigue diurnal profiles

To explore whether different subgroups could be distinguished based on the fatigue diurnal profiles, latent class growth analysis was performed. Latent class growth analysis aims to capture heterogeneity in the daily course of fatigue by classifying patients into an optimal number of classes, each with a unique profile of diurnal fatigue.[24] A forward approach was used to determine the optimal number of classes.[25] Assuming that all participants have the same profile, a first model with one diurnal fatigue profile was used. Then, another profile was subsequently added each time after which the model fit was assessed. To determine the optimal number of profiles, we used the Bayesian information criterion; lower values indicated a better model fit. Finally, graphical representations of each model and clinical reasoning were used to determine the model with the most feasible diurnal profiles. Hereafter, each participant was assigned to the class with the highest probability of membership.

Predictors of real-time diurnal fatigue profiles

We used univariable multinomial logistic regression analysis to explore predictors for diurnal fatigue profiles. Separate analyses were run for each of the participant characteristics (sex, age, CP type, and GMFCS level) and potential physiological predictors (sleep, physical behaviour, aerobic capacity, BMI, and fat mass). Odds ratios (OR) with 95% confidence intervals (CI) are presented for each characteristic or predictor. A *p*-value of lower than 0.05 was used to determine statistical significance.

RESULTS

Participants

Thirty-two adults with CP (median age 29 years 8 months [IQR 24 years 7 months–40 years 3 months], range 20–54 years) participated in this study; patient characteristics are presented in Table 1. All participants responded to the real-time diurnal fatigue assessment using four daily SMS texts for 7 days. The overall diurnal RTFS was on average 4.5 (SD 1.8). During the day, RTFS varied from 3.5 (SD 1.9) at 9 am to 5.4 (SD 2.0) at 9 pm. After the latent class growth analysis model fits, the three-class model was deemed to be the best model, identifying three different fatigue profiles: a stable low fatigue profile ($n = 10$), an increasing fatigue profile ($n = 14$), and a stable high profile ($n = 8$; see Figure 1).

Adults with CP in the increasing fatigue profile progressed from the lower end of moderate fatigue to the higher end of moderate fatigue (fatigue score 3–6) during the day. The adults with CP in the stable low fatigue profile got up in the morning and remained around the same level of moderate fatigue during the day (fatigue score about 2–3). The adults in the stable high profile got up in the morning at the higher end of moderate fatigue (fatigue score 5.9) and progressed to the lower end of severe fatigue (fatigue score 7.3) in the evening. At the end of the day (at 5 pm and 9 pm), 22 adults with CP were at the higher end of moderate or lower end of severe fatigue (fatigue scores 5.3–7.3).

Sleep, physical activity, and health-related fitness

One participant did not perform the maximal exercise test because of anxiety. In four participants the Activ8 showed data for less than 3 days. These participants were excluded from the analyses in which aerobic capacity and physical activity were used as predictors. Table 1 displays the participant characteristics per profile, as well as the descriptive values of the outcome and predictor variables. Besides the overall RTFS ($p < 0.001$), there were no significant ($p = 0.12$–0.94) differences between diurnal profiles.

Associations with real-time diurnal fatigue profiles

Aerobic capacity significantly predicted whether a person was in the increasing rather than in the stable low group ($b = 0.14$, Wald $\chi^2[1] = 3.85$, $p = 0.05$). People with a higher aerobic capacity had higher odds of being in the increasing than in the stable low group (OR 1.16, 95% CI 1.00–1.34). There were no further significant associations ($p = 0.07$–0.97) between potential predictors and fatigue profiles. The results of the multinomial logistic regression analyses are shown in Table 2.

DISCUSSION

In this exploratory study, we found three patterns of daily fatigue. Pattern 3 had the most fatigue, which was fairly stable over the day. Pattern 2 started with low levels of fatigue that increased over the day. Pattern 1 had low levels of fatigue, which was fairly stable over the day. Our secondary aim was to explore whether patient characteristics (age, CP type, and GMFCS level), sleep, physical activity, and components of health-related fitness could predict the fatigue profiles. Aerobic capacity, a component of health-related fitness, was significantly associated with the increasing versus the stable low profile.

The findings from our study suggest that real-time fatigue assessment captures actual fatigue experience and moment-to-moment variations. This might be of importance, since it has been shown by this and other studies looking at fatigue in adults with CP that fatigue perception may very well depend on the moment of assessment.[5,9,26] Knowledge about moment-to-moment or even day-to-day variations in fatigue may be helpful for tailored and personalized advice. This real-time fatigue assessment has not been used previously in individuals with CP. Former studies in individuals with CP often used the Fatigue Severity Scale or the Fatigue Impact and Severity Self-Assessment as a measure of fatigue.[3,27] However, these and other fatigue instruments ask participants to evaluate their fatigue status retrospectively (i.e. fatigue during the past week). This approach requires persons with CP to remember their fatigue during the past period,

TABLE 1 Participant characteristics, outcome, and predictors

Characteristics	All participants (n = 32)	Stable low (n = 10)	Increasing (n = 14)	Stable high (n = 8)	p
Age, median (IQR), years:months	29:8 (24:7–40:2)	36:5 (30:6–40:8)	27:2 (23:5–40:1)	28:6 (24:5–40:6)	0.19
Sex, n					
Male	11	3	5	3	0.94
Female	21	7	9	5	
CP type, n					
Unilateral spastic	22	8	8	6	0.45
Bilateral spastic	10	2	6	2	
GMFCS level, n					
I	9	1	6	2	0.42
II	15	5	6	4	
III	8	4	2	2	
Outcome					
Real-time overall fatigue score					
RTFS day average, mean (SD)	4.5 (1.8)	2.4 (1.0)	4.7 (0.6)	6.6 (0.6)	<0.001
Predictors					
Sleep					
PSQI score, median (IQR)	8.5 (6.0–9.8)	9.0 (4.0–11.3)	6.0 (6.0–9.0)	9.0 (6.0–10.5)	0.37
Physical activity (n = 28)					
Physical activity (% of wear time), mean (SD)[a]	23.1 (12.3)	18.1 (10.1)	23.5 (11.8)	29.0 (15.1)	0.23
Health-related fitness					
BMI (kg/m^2), median (IQR)	23.9 (21.7–28.1)	22.9 (21.6–27.1)	24.0 (21.5–27.3)	26.4 (20.3–30.0)	0.84
Fat mass (%)	28.0 (9.5)	29.4 (12.7)	26.4 (8.5)	29.6 (7.1)	0.69
Aerobic capacity (ml/kg/min)[b]	31.4 (7.3)	27.4 (8.0)	33.9 (6.1)	31.4 (7.3)	0.12

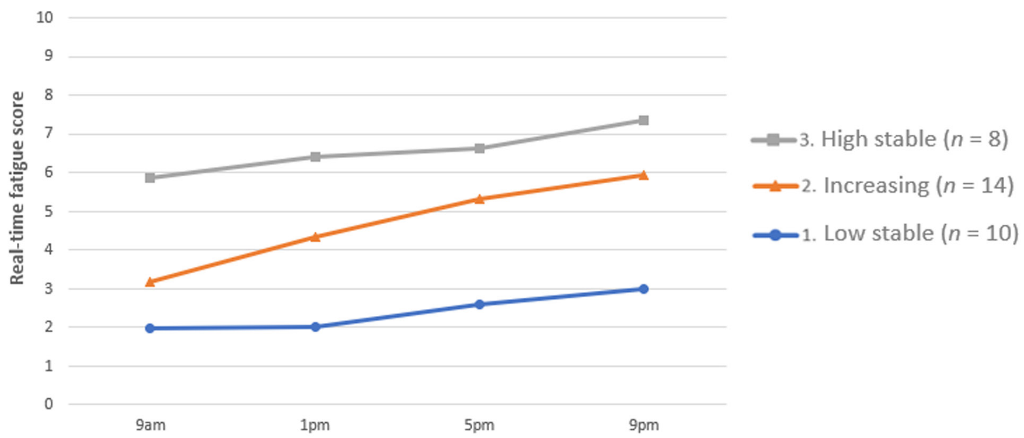
[a] n = 28.
[b] n = 31.
Abbreviations: BMI, body mass index; GMFCS, Gross Motor Function Classification System; IQR, interquartile range; PSQI, Pittsburgh Sleep Quality Index; RTFS, real-time fatigue score.

but additionally to average these perceptions over time, a cognitively demanding task that might be challenging for people with CP. Real-time assessment of fatigue may thus be more feasible and accurate to analyse fatigue complaints in this population.

The three different diurnal fatigue profiles in adults with CP that could be distinguished acknowledge the interindividual differences in this heterogeneous population. The within-day (i.e. diurnal patterns) variations in fatigue perception may benefit both research and clinical practice, such as specifying fatigue research, and selecting potential study participants. It can also be used to identify whether or not fatigue should be a treatment goal and, if so, how to approach it.

Unfortunately, there are no evidence-based interventions to reduce CP-related fatigue. However, extensive rehabilitation experience and some literature show that people may benefit from fatigue management. This was studied by Brunton et al.,[27] who observed significant differences between adolescents with CP and typically developing peers in the Management and Activity Modification subscale of the Fatigue Impact and Severity Self-Assessment. Based on their findings they concluded that young people with CP may try to self-manage the impacts of fatigue in their day-to-day life to a greater extent than their typically developing peers. They also speculated that for young people with CP, fatigue may have a larger impact on daily activities.

In our exploratory analyses of potential predictors of fatigue profiles, we found that only aerobic capacity was a significant predictor. When aerobic capacity increases in adults with CP, the odds of being in an increasing fatigue profile rises. This finding was surprising, but might be explained by the fact that people who are more fit are usually more active in various ways and may rest less during the day. It might be that this group of adults with CP push through physical (and mental) barriers during the day. A paper by Brunton et al.[28] provides example quotes from people with CP who talk about reaching their limits or not recognizing those limits until they are too late. The authors state that the self-awareness of people with CP and the impact of fatigue should be fostered by service providers and included in clinical conversations about managing their health care needs



	9am	1pm	5pm	9pm
3. High stable (*n* = 8)	5.87 (0.94)	6.40 (0.75)	6.63 (0.66)	7.35 (0.91)
2. Increasing (*n* = 14)	3.17 (1.06)	4.35 (0.84)	5.33 (0.99)	5.94 (1.12)
1. Low stable (*n* = 10)	1.96 (1.54)	2.02 (1.15)	2.61 (1.17)	2.98 (1.28)

FIGURE 1 Real-time fatigue diurnal profiles

TABLE 2 Multinomial logistic regression

	Univariable			
	Increasing vs stable low		Stable high vs stable low	
	OR (95% CI)	*p*	OR (95% CI)	*p*
Characteristics				
Female vs male (reference)	1.30 (0.23–7.38)	0.77	1.40 (0.20–10.03)	0.74
Age	0.93 (0.84–1.02)	0.13	0.94 (0.84–1.05)	0.29
CP type				
Unilateral spastic (reference)	1.0	-	1.0	-
Bilateral spastic	3.00 (0.46–19.59)	0.25	1.33 (0.14–12.37)	0.80
GMFCS level				
I (reference)	1.0	-	1.0	-
II	0.20 (0.02–2.27)	0.19	0.40 (0.03–6.18)	0.51
III	0.08 (0.01–1.26)	0.07	0.25 (0.01–4.73)	0.36
Sleep				
PSQI score	0.83 (0.61–1.12)	0.22	0.99 (0.71–1.39)	0.97
Physical activity				
Physical activity	1.04 (0.96–1.12)	0.30	1.08 (0.99–1.18)	0.09
Health-related fitness				
BMI	0.97 (0.84–1.12)	0.66	0.99 (0.85–1.16)	0.92
Fat mass	0.97 (0.88–1.06)	0.45	1.01 (0.90–1.11)	0.98
Aerobic capacity	1.16 (1.00–1.34)	**0.05**	1.10 (0.94–1.28)	0.23

Bold type indicates statistical significance. Abbreviations: BMI, body mass index; CI, confidence interval; CP, cerebral palsy; GMFCS, Gross Motor Function Classification System; OR, odds ratio; PSQI, Pittsburgh Sleep Quality Index.

for the present and the future. The use of the RTFS to assess fatigue for people with CP could serve as a starting point to have clinical conversations and to determine strategies for managing fatigue.

In our exploratory study, we included adults with CP with complaints of fatigue during daily physical activities. We found that 76.9% (SD 12.4) of wake time was spent in sedentary activities. This finding is comparable to the results of a combination of studies that studied objectively the physical activity levels of people with CP and found that persons with CP spent 76% to 99% of their waking hours sedentary.[29] We also found that 84% of the adults included in this study reported poor sleep, which is close to the findings of a recent study that reported poor sleep quality in 75% of the participants (adults with CP without specific complaints of fatigue).[30] Ellingson et al. found that meeting physical activity recommendations is beneficial for fatigue, even when combined with an otherwise sedentary lifestyle.[31]

Strengths and limitations

This study has several strengths and limitations. The real-time fatigue assessment, the extensive physical activity measurement using an objective measure, and the different studied aspects of physical health (aerobic capacity, BMI, and fat mass) were among the main strengths of this study. There were, however, also limitations in the study. First, since results generated from small sample sizes are prone to error, the current results should be interpreted with caution. The small sample size did not allow for multivariate testing; equally, we also did not correct for multiple testing. However, this is the first time fatigue has been measured in real-time, and therefore the predictors can be considered explorative. Second, the data represent patterns of fatigue and physical activity (for 28 of 32 participants) for only 1 week, and, as such, might not be representative of fatigue patterns over longer periods. Third, the findings from this study are derived from a group of ambulatory adults with CP with complaints of fatigue during daily activities with limited ability to perform intensive physical activities and are therefore not representative for a larger cohort of adults with CP without complaints of fatigue or those who are classified in GMFCS levels IV and V (non-ambulatory).

Conclusions

We identified three interindividual fatigue profiles by real-time assessed fatigue. These profiles suggest different fatigue patterns in ambulatory adults with CP. These findings indicate the relevance of assessing fatigue variability in clinical practice and may be relevant for daily clinical practice to analyse fatigue complaints and help personalize fatigue management.

ACKNOWLEDGMENTS

We would like to thank all participants of this study, Susan Blom-de Heer for her help with data collection, and Lars van Loo and Jorinde Scholten for their help with data analysis. We also thank Annet Dallmeijer for her contribution throughout the project.

We certify that no party having a direct interest in the results of the research supporting this article has or will confer a benefit on us or on any organization with which we are associated and that the results of this study do not constitute an endorsement by ACSM. AB is a postdoctoral researcher on the funding of a grant from La Fondation Motrice. For the remaining authors, no disclosures were declared.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ORCID

Olaf Verschuren https://orcid.org/0000-0002-4443-5327
Wilma M. A. Van Der Slot https://orcid.org/0000-0001-9954-4603

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How to cite this article: Verschuren O, Benner JL, Balemans ACJ, Horemans H, Van Den Berg-Emons RJG, Van Der Slot WMA. Real-time daily fatigue, sleep, physical activity, and health-related fitness in adults with cerebral palsy. Dev Med Child Neurol. 2022;00:1–8. https://doi.org/10.1111/dmcn.15421